

It's not just 'What' you do, it's also the 'Way' that you do it: Patient and Public Involvement
in the Development of Health Research.

Running title: Patient and Public Involvement

Abstract

Purpose: This paper presents a reflective account of Patient and Public Involvement (PPI) in the development of obesity and binge eating research.

Method: We established Patient Advisory Groups (PAGs) at two English regional National Health Service (NHS) weight management services. PPI was evaluated as follows; (1) PAG members completed a PPEQ, (2) PAG meetings captured group discussion on PPI involvement, (3) practitioner and researchers produced written reflections on PPI, (4) sources one to three were consolidated during reflections that took place via e-mail and telephone correspondence between researchers and practitioners, culminating in a summary SKYPE meeting between one practitioner and one researcher involved in the PAGs.

Results: Results in the form of reflections suggest guidelines on undertaking PPI were helpful with regards *what* to do, but less helpful on *how*. For example, suggestions for the management of interpersonal factors such as eliciting self-disclosure and managing power differentials are insufficiently addressed in existing guidelines.

Conclusions: The present case study illustrated how interpersonal considerations can help or hinder the optimal use of PPI. Recommendations for practitioners and researchers planning PPI are offered.

Keywords: relational dynamics; self-disclosure; communication, patient satisfaction, shared decision making, qualitative methods.

1 Introduction

2 As early as 1993, UK government guidance of health research has shown a policy
3 commitment towards consumer involvement (Patient and Public Involvement: PPI). With the
4 explicit objective of promoting PPI in research; and with support from the Department of
5 Health, the national advisory group INVOLVE was established in 1996. Its function is to
6 promote the active involvement of service users (patients) and carers, in the design, conduct,
7 analysis and reporting of research [1].

8 INVOLVE [2] surmise that meaningful engagement of the public benefits research
9 via: a) feasibility, acceptability, accessibility and relevance of hypotheses, assisting in the
10 more precise definition of research questions, and, b) increased adherence to experimental
11 protocols [3]. PPI should enhance the quality of research by producing research that is
12 focussed on patient objectives, developing user-friendly participant materials, and having
13 more appropriate recruitment strategies [4, 5]. Where PPI is well planned, members can gain
14 new skills and experience, feel more valued, respected and better represented. They may
15 bring new insights and momentum to the research and dissemination processes [4, 6].

16 We aimed to meet INVOLVE guidelines in this case study inviting patients and
17 practitioners to validate research questions and help establish methods of investigation with
18 regards the design, testing and evaluation of an intervention targeting emotional eating. This
19 case study presents reflections on this process and proposes recommendations to help
20 optimise future PPI [7].

21 Method

The focus of this paper is on evaluative data gathered in phase four however, the method is detailed in full to provide context.

Participants

Patient Advisory Groups (PAGs) were formed at two English regional NHS weight management services. PAG members were BED-obese patients accessing weight management services (female $n = 8$; male $n = 2$), or professionals (female $n = 2$; male $n = 1$) working with this group. On advice from the local NHS R&D representative, one male patient volunteer with experience of PPI was also recruited. During the evaluation phase the two researchers (facilitating the PAGs) two lead practitioners (involved with patient participants but not PAGs) and one PAG practitioner debated the reflective accounts and outcomes of PPI.

Measures

Post Participation Evaluation Questionnaire

The Post Participation Evaluation Questionnaire (PPEQ) [8] comprised five questions that sought to examine PAG experiences with PPI, with opportunity to provide additional unstructured feedback.

Procedure

Following favourable ethical review from the NHS Integrated Research Approval System (IRAS), prospective members of the PAG were identified by the lead practitioner at each site. Volunteer participants completed a consent form.

Phase 1: Initial Consultation

Participants were provided with a booklet providing a lay summary of relevant research findings [9]. Patients were invited to answer open ended questions in response, either via a booklet, or online survey. For example, *'If there was something you would like us to be able to explain now about emotional eating, what would it be?'* Responses were collated and illustrative quotes selected on the basis of relevance and frequency. These were anonymised and presented via PowerPoint at the PAG meetings for discussion.

Phase 2: Initiating Collaboration

PAGs met at their respective NHS site. Two meetings were held with a period of consultation in between. The first PAG meeting began with an informal induction by way of a group discussion to help contributors understand their roles during PPI and develop confidence in voicing opinions. Thereafter, anonymised patient quotes from phase one were presented as a basis to stimulate further discussion with the aim of addressing: a) who should participate in the study of emotional eating among BED-Obese populations; b) what methods would be most acceptable; and c) what are the pressing issues in this specialism [1].

Phase 3: Ongoing Consultation

PAG members responded to four open ended online surveys to discuss methods of data collection, acceptability of specific research protocols, and preferences for outcome measures. PAGs met a second time to reflect on the outcome of the online surveys and to contribute to an evaluation of PPI.

Phase 4: Evaluation

PPI was evaluated by four methods; (1) PAG members completed the PPEQ [8], (2) a second round of PAG meetings captured group discussion on their involvement in the

research, (3) practitioner and researcher teams produced written reflections, and finally (4) these were consolidated during reflections that took place via e-mail and telephone correspondence between researchers and practitioners, culminating in a summary SKYPE meeting between one practitioner and one researcher involved in the PAGs. A counselling psychologist convened this SKYPE meeting to help extrapolate key lessons learned from the PPI.

Analysis

Verbal data were taped and transcribed; questionnaire and electronic data were collated. Data were analysed by the first two authors after each phase, and key findings were extracted through content analysis. In the first PAG, findings from the booklets were reviewed and verified. Following this, online consultation and feedback was used to verify the findings from the first PAG. New data obtained via ongoing consultation were then taken to the final PAG. In this way we systematically triangulated findings across different sources of data, and used member checking to verify that the most pertinent and representative information had been collated.

The reflective exchanges reported in the present case study were collected in phase four. The following presents a review of the PPI process from patient, practitioner, and researcher perspectives.

Results and Discussion

(i) PPEQ

PPEQ data indicated that all members felt it was easy to talk during PAG meetings, that this was perceived to be helpful, and that the researchers were understanding. Open

1 PPEQ feedback indicated that the meetings were *'open and relaxed, clear that opinions and*
2 *feedback are welcomed and appreciated.'* One member commented that she felt *'...part of*
3 *the group and not just a statistic'*. Whilst some reservations were expressed, for example;
4 *'was a bit skeptical to start with'*, all members expressed a desire to continue their
5 involvement where possible. One member noted; *'I have really enjoyed the involvement of*
6 *the group. I found it very interesting and would happily participate in the future'*. Two PAG
7 members had proactively contacted the research team to enquire about the opportunity for
8 continued involvement.

9 (ii) PAG Meetings

10 Complementing findings from the PPEQ, patients reported satisfaction with the PPI
11 process during PAG meetings. One PAG member, reflected:

12 *I was impressed with the way participants were willing to divulge details of*
13 *a personal nature around the compulsions that led them to use food to*
14 *affect mood. I attribute this to the professionalism of the research team who*
15 *were able to create an atmosphere of trust among the participants so that a*
16 *supportive and non-threatening atmosphere permeated proceedings.*

17 In this case study, participation in PPI was reported to be of benefit, empowering, and
18 enjoyable; largely as a result of knowledge sharing and discussions regarding common
19 interests [1]. This was illustrated in the following discussion:

20 PAG member1: *I've been hearing other people's experiences and I'm*
21 *coming up with some answers.*

1 PAG member2: *I volunteered to just understand really, why we*
2 *emotionally eat and so... even just like walking up here [for the PAG], it*
3 *starts you thinking about it.*

4 Reflections from the PPEQ and PAG meeting indicated high levels of patient
5 satisfaction with PPI experiences. This suggested that we had achieved our aims of
6 collaboration to inform the development of a relevant research proposal.

7 *(iii) Practitioner Reflections*

8 During the PAG launch information collected from patients in a Pre-PAG information
9 booklet (Phase 1) were presented by the academic partners in a PowerPoint presentation.
10 Two practitioners involved with one of the two weight management services (one involved in
11 the PAG, one not) felt this information was presented as the ‘right answers’ and suggested
12 this may have constrained the subsequent discussion by influencing PPI freedom to respond
13 or disagree. They also felt that using PowerPoint was a subtle but powerful way of the
14 researchers establishing their ‘expert credentials’ despite, ironically, having the least amount
15 of ‘legitimate’ knowledge and direct experience in working with emotional eating.
16 Practitioners reported feeling that their expertise was somewhat de-legitimised and suggested
17 that PAG patient members felt both ‘led’ and unable to challenge the researcher led
18 knowledge. These perceptions are captured in the written reflections offered by the
19 practitioner co-author (not involved in PAGs) below:

20 *As a former academic, who has returned to clinical practice, I did not*
21 *personally experience the same response to the academic psychologists as my*
22 *colleagues or patients; yet I was able to recognize how academic credentials*

1 *can appear more 'legitimate' than a patient or practitioner's long history of*
2 *direct clinical experience. Both patients and practitioners reported to me,*
3 *privately, that they wanted to raise some issues but they had felt unable to do*
4 *so because the PAG was being led by 'experts from the University'. Some felt*
5 *they had been 'steered' in a particular way to address a pre-set list of*
6 *questions. Knowing the extent to which the academic partners tried to*
7 *genuinely involve the patients and practitioner in the research process these*
8 *comments felt very frustrating.*

9 This highlights how difficult it is to truly involve patients and practitioners in a
10 collaborative process. Genuine intentions may be overruled by underestimated tacit power. It
11 takes time, effort, and clinical skill, to develop a level of trust where patients feel able to talk
12 about the underlying reasons for their disordered eating. This practitioner reported concern
13 about the research psychologists' lack of clinical experience, and perceived understanding of
14 the complex aetiology underlying eating disorders and capacity to fully establish a
15 collaborative client-centred process. This was experienced as a tension between personal
16 interest in supporting a 'good' research process, and the service driven need for research
17 involving treatment protocols for complex co-morbid conditions, not simply more
18 information about the consequences of such.

19 *Researcher Reflections*

20 Our PPI was confined by the availability of funding and regional and national health
21 priorities. As such, we did not use an emancipatory approach to "identify and prioritise" a
22 research topic. In accordance with INVOLVE guidelines [1], our aims for PPI were to

1 validate research questions and gain information on the accepted methodology for the
2 proposed research. We believed that we were thorough in validating our research questions,
3 and that the design of the resultant research was a product of effective collaboration with the
4 PAGs.

5 Finally, as researchers operating in a sensitive area, we prioritised the design of a safe
6 and ethical process. Researchers were careful not to delve into the underlying reasons for
7 patient practitioners disordered eating. These concerns were captured in the reflections of one
8 academic research lead:

9 *As a non-clinician going into those meetings I'll admit that I had a certain*
10 *level of nervousness about it because you know you are dealing with a*
11 *potentially vulnerable group, and that's why working with [names clinical*
12 *practitioner colleague], I knew I had them there in a support role, I thought*
13 *that was a strength of working as a group of researchers and practitioners*
14 *together. I personally gave thought to what would I do if a patient member got*
15 *distressed in one of the groups, how would I manage that.*

16
17 *(iv) Consolidation of PPEQ, PAGs and written reflections*

18 An important point emerged that we advocate be noted in future research involving
19 PPI. Despite patient PAG members reporting that they felt they could be open and honest,
20 practitioners noted that these same patients reported the opposite to them. Indeed, a
21 practitioner PAG member noted that during meetings patients *'were giving their opinions and*
22 *I'm thinking, 'that's not what you think', and I couldn't really say that in front of them... I*

1 *knew their issues were much deeper than they were letting on publicly*'. Issues of patient-
2 disclosure and the tensions posed by 'privileged' knowledge in a team of academic and
3 practitioner researchers present a critical learning point.

4 The PAG practitioner who noted a discrepancy in the disclosures offered by patient
5 PAG members suggested that involving practitioners who did not know PAG members as
6 patients may have encouraged greater patient honesty. This is a potential recommendation to
7 take forwards from this case study. Paradoxically, we noted that incongruence of patient
8 disclosure between researchers and practitioners may not have been identified without
9 practitioner input.

10 There were multiple dynamics at play in the PAGs which may have influenced patient
11 member's contributions. Practitioners and researchers had different priorities with regards the
12 PAG discussions. Whereas researchers wished to validate health research questions and
13 establish methods of investigation through PPI, practitioners were interested in clinical case
14 formulation and found discussions to be superficial. Such tensions are inherent in fitting
15 clinical and patient centered research to the requirements of a funding call. Thus, we
16 encourage those embarking on PPI to carefully consider the presence and possible influence
17 of dual relationships whereby PAG members occupy a dual-role of researcher and
18 practitioner relative to patient PAG members.

19 In looking to improve communication, researchers and practitioners agreed that the
20 use of a PowerPoint presentation to communicate patient generated examples of emotional
21 eating created a formal atmosphere to the initial PAG meeting, and potentially established an
22 unhelpful early impression of the researchers as experts. The PAG practitioner reflected

1 during the concluding SKYPE discussions; *'I think probably the patients had you and*
2 *[mentions second researcher] up here [uses hand to illustrate elevated status] 'cause they*
3 *would have thought, these are academic people from a University'*. The SKYPE mediator
4 enquired how the participating academic and practitioner felt about these perceived
5 differences:

6 Practitioner: *I think at first I was a bit like, oh god they're gonna know loads,*
7 *you know they work in a University they've got a lot of qualifications...*

8 Researcher: *That's something we're trying to avoid because people have an*
9 *expertise we just don't have. So how could we try and have more of a level*
10 *playing field?*

11 Discussion and Recommendations

12 From our reflective discussions, factors emerged that had not been adequately
13 acknowledged or addressed within the PPI process, but had nevertheless impacted upon the
14 sincerely intentioned collaborative enterprise. Critical learning points taken from these
15 reflections were:

16 i) *Attain clarity of PPI purpose and resolve differences in aims and priorities.*

17 Different perspectives are common in multi-disciplinary teams [10]. In the present study, the
18 challenges posed when practitioners undertake research with their patients in relation to PPI
19 aims, disclosure, confidentiality, and ethics were highlighted. Copeland [11] suggests that the
20 best outcomes are achieved when everyone is clear about their roles, boundaries, how these
21 interface with each other and the wider culture, and how the enterprise contributes to the
22 common good. Ballatt and Campling [12] describe this level of co-operation as 'kinship'

1 which promotes kindness (p. 44), with behavior contributing to a whole systemic process
2 which reduces anxiety and defensiveness promoting the conditions necessary for compassion
3 to be modelled by everyone involved. Gutteridge and Dobbins [13] report that the time and
4 resources necessary to establish effective PPI partnership working is frequently under-
5 estimated. The current INVOLVE guidelines do not consider the inter-personal dynamics of
6 partnership working.

7 ii) *Support relevant disclosure whilst managing risk and safety, balanced alongside*
8 *the ethical principles of respecting patient autonomy and confidentiality.* This is a crucial
9 consideration and perhaps the most challenging dilemma for which we could agree the fewest
10 solutions. There is debate dating back many years which suggests others find this aspect of
11 research difficult to resolve [14, 15]. Goffman [16] suggested that in unfamiliar situations,
12 people may protect themselves by managing information and limiting self-disclosure.
13 Cornwell [17] found that public accounts were more likely in response to a direct question,
14 whereas private accounts are more likely to be elicited by invitations to tell a story. She
15 suggests this occurs because the invitational approach shifts power subtly towards the
16 participant. There seems to be consensus that time is necessary to build the trust required to
17 support appropriate self-disclosure.

18 iii) *From the earliest planning phase pay attention to relational dynamics,*
19 *particularly perceived power and to the methods used to communicate so that tacit mixed*
20 *messages are minimized.* Harrison and Williams [18] wrote about the different forms of
21 power and authority available to health professionals in their transactions with others,
22 concluding that greater awareness of the ways these were transmitted, experienced and

1 interpreted, could facilitate wiser use of power, particularly where there are real or perceived
2 imbalances.

3 To counteract potential imbalances in knowledge which may lead to a power
4 differential, the INVOLVE guidelines [1] advocate the training of PPI members, but this is a
5 contentious issue as it has been suggested that training PPI contributors is not always
6 desirable [19]. As an alternative to formal training, as recommended by Dudley et al. [19],
7 the present study used an informal induction. The inclusion of a short PowerPoint
8 presentation, intended to facilitate information transmission and free up time for discussion
9 had an adverse effect on informality and contributed to perceptions of power imbalance,
10 something we did not foresee.

11 iv) *Create opportunities to share and establish 'difference' as a valued component of*
12 *the research process.* Attention to underlying tensions can be seen as encouraging conflict to
13 develop or as a diversion from the task, but we suggest such time investment may be cost
14 effective in the longer-term. Pratt, Gordon, and Plamping [20] proposed a typology of
15 partnership behavior intended to help project groups appraise the type of collaboration and
16 involvement desired, and facilitate the behaviors most likely to meet the needs of the
17 partnership at different stages of evolution (see Figure 1).

18
19 [Insert Figure 1 about here]
20

1 Resilient, effective partnerships contain elements of all four quadrants and are likely
2 to move between them over time, but Pratt et al. [20] acknowledge there may not be time in
3 short projects to move through all the stages needed for sustainable relationships.

4 v) *Acknowledge constraints and limitations so these can be addressed.* Well
5 intentioned and motivated individuals may inadvertently take on too much, then feel guilty
6 and obligated, which can breed undercurrents of discontent, instead of honest, if challenging,
7 discussion. These are genuine tensions, particularly for practitioners expected to be research
8 active. There is growing acknowledgement, particularly in the NHS, that these tensions may
9 be irreconcilable [21]. Similarly, researchers (who may tend to adopt a leadership and project
10 management role) may need at times to show their own uncertainty and vulnerability. Orlans
11 and Edwards [22] describe this type of disclosure as ‘*double loop learning*’ (p. 46), where all
12 parties engage in shared learning with mutual benefit. Such dialogue is an essential
13 component of a collaborative approach.

14 These considerations, pivotal to success, are not currently addressed in PPI
15 guidelines. We do not suggest any guidelines could offer a comprehensive overview that
16 would have helped to avoid the issues encountered. Nevertheless, we would have valued
17 specific prompts to think more proactively about relational aspects and power dynamics.

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